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Development of the international prolonged grief disorder scale for the ICD-11: Measurement of core symptoms and culture items adapted for chinese and german-speaking samples

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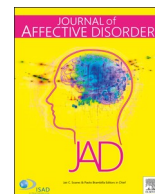


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Research paper

Development of the international prolonged grief disorder scale for the ICD-11: Measurement of core symptoms and culture items adapted for chinese and german-speaking samples



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ABSTRACT

Background: Prolonged grief disorder (PGD) is a new mental health disorder included in the WHO ICD-11 however, the operationalization of the guidelines still needs to be empirically validated, particularly in different cultural contexts. Here we provide a preliminary validation study of the new International Prolonged Grief Disorder Scale (IPGDS) that serves to be the first self-report questionnaire directly based on the ICD-11 PGD and contains culturally adapted items.

Methods: In addition to core symptom items new culturally specific items were developed in two phases. Phase 1: key informant interviews with 10 German-speaking and 14 Chinese experts in grief and mental health, followed by a focus group with four bereaved German-speaking participants. Phase 2: 214 German-speaking and 325 Chinese bereaved participants completed self-report questionnaires.

Results: Phase 1 resulted in 19 potential culturally relevant items (e.g. feeling stuck in grief). Phase 2 exploratory factor analysis confirmed the one-dimensional nature of the IPGDS, additionally the 32-item scale revealed two factors (core grief and culturally specific symptoms). Psychometric analysis revealed strong internal consistency, concurrent validity and criterion validity.

Limitations: The German-speaking and Chinese samples significantly differed in terms of several demographic variables including age, gender and type of loss.

Conclusions: This preliminary validity study confirms that the IPGDS is a valid and reliable measure of the new ICD-11 PGD guidelines. This is the first scale of disordered grief to contain both core items and culturally specific supplementary items and aims to improve the clinical utility of the ICD-11 narrative approach.

1. Introduction

In 2018, the new prolonged grief disorder (PGD) guidelines for diagnosis were introduced by the World Health Organization in the 11th revision of the International Classification of diseases (ICD) (Killikelly and Maercker, 2017; World Health Organization, 2018). This has energized researchers and led to an increase in publications and international research efforts to validate and clinically assess these guidelines to confirm their usability in research and practice (Boelen et al., 2018; Mauro et al., 2018). The ICD-11 has revised these guidelines to enhance clinical utility and improve the global applicability of mental disorder criteria by including culturally specific features (Keeley et al., 2016; Maercker et al., 2013). Evidently these

changes are not without challenges. Although the new guidelines are based on previously validated criteria (PGD-2009) (Prigerson et al., 2009) and the preliminary validation of these guidelines has been confirmed (Maciejewski et al., 2016) the operationalization of these new criteria in research and clinical practice has led to concerns from researchers and clinicians (Boelen et al., 2019; Eisma and Lenferink, 2018). For example, there is a no specification for the threshold of diagnosis, confusion over symptom context for example, specific item examples are needed and uncertainty about how to include culturally specific symptoms of disorder (Boelen et al., 2018; Lenferink et al., 2019; Stelzer et al., 2020). The first step towards further validating these criteria is to provide researchers and clinicians with a validated assessment measure of PGD based on the new ICD-11

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criteria. Ideally, this assessment measure would be developed following the new guideline for improved clinical utility and global applicability. Here we introduce the International Prolonged Grief disorder scale (IPGDS), which is the first scale to assess symptoms of PGD according to the new ICD-11 criteria and provides a possible method for how to operationalize global applicability through culturally adapted items. The IPGDS assesses PGD symptoms that are believed to be pan-cultural or core symptoms of disordered grief along with a culturally specific supplement.

With the emergence of cultural psychiatry, global mental health and cultural clinical psychology, the universality of mental disorders has been widely questioned (Kirmayer and Ban, 2013; Kleinman, 1978; Ryder and Chentsova-Dutton, 2014). Recently, Chinese and Swiss bereaved parents completed a precursor version of the IPGDS. It was found that Chinese parents more strongly endorsed symptoms of emotional pain and functional impairment whereas Swiss parents endorsed preoccupation with the deceased (Xiu et al., 2016). This variability in symptom presentation can affect the validity of prevalence rates and lead to misdiagnosis (Kleinman, 1977; Stelzer et al., 2020c). Yet, grief is a universal phenomenon that is documented in almost every human culture (Rosenblatt, 2008).

The universalist approach—or more modestly labelled pan-cultural approach—suggests that mental disorders have core symptoms of internal pathology. Our recent study using the same sample explored PGD in German-speaking and Chinese samples using a network analysis. We confirmed the presence of a core network of grief consisting of symptoms of yearning and emotional distress in both German-speaking and Chinese participants (Stelzer et al., 2020a; Stelzer et al., under review). In addition, we showed that the predictive power of diagnostic criteria can be enhanced if culturally sensitive symptoms are added.

There is little consensus to what degree symptoms of mental disorder are pan-cultural or specific to cultural context. Due to methodological limitations including difficulty in identifying biological markers, lack of consensus on diagnostic definition (i.e. different criteria for ICD and DSM disorder definitions), different measurement tools (i.e. no gold standard), it is difficult to draw clear conclusions (Canino and Alegria, 2008). For example, even within one culture different diagnostic rates of disorder can be found due to methodological imprecision (Boelen et al., 2018; Lenferink et al., 2019). Here we attempt to rectify this issue by developing the IPGDS with the aim to provide clinicians and researchers with a pan-cultural yet culturally adaptable tool with good reliability and validity. To establish the psychometric validity of the IPGDS **Table 1 (in the supplementary material)** presents the reliability and validity analyses that were conducted including a rationale for each analysis.

1.1. Development of the IPGDS: two subscales

Currently, several validated self-report measures of disordered grief exist (Boelen and Smid, 2017; Lee, 2015; Prigerson and Jacobs, 2001; Prigerson et al., 1995). The items in these measures are based on previous proposals for either PGD (i.e. Prigerson et al., 2009) or the persistent complex bereavement disorder (PCBD) for the DSM-5, however there is no measure for the new ICD-11 PGD guidelines. In order to develop the new ICD-11 scale we chose validated items from the PG-13, ICG-R and the Structured clinical interview for complicated grief (SCI-CG) (Bui et al., 2015) to construct a 13-item scale with two screening questions (time and cultural caveat criteria, see methods). In line with the guidelines of the WHO for improved clinical utility and global applicability, we employed a bottom up approach and developed a cultural supplement of 19 items that are culturally relevant to German-speaking and Chinese bereaved. The cultural supplement was developed from key informant interviews with 10 German-speaking and 14 Chinese health care workers specializing in grief and mental health (see Stelzer et al., 2020b). Key informants identified culturally specific items that are currently missing from the ICD-11 definition of PGD. This

resulted in the new composition of the IPGDS with a standard scale of 13 core items specific to the ICD-11 PGD definition and a cultural supplement of 19 additional items that are purported to capture grief symptoms across each culture. These items were assessed within and between cultural groups to compare the validity.

This study has two main aims: firstly, the development of the IPGDS by bottom up qualitative interviews and secondly, to establish the psychometric validity of the IPGDS across two different cultures. In particular, the validity of the core items (standard 13-item) will be evaluated as well as the validity of the whole scale (32 items). Recommendations for clinical use and further research directions will be discussed.

2. Methods

2.1. Part 1 IPGDS development

The procedure and analysis of the key informant interviews is described in detail in (Stelzer et al., 2020b). Briefly, the IPGDS was developed in two scales. The first scale is a *standard scale* that includes 15 items based specifically on the new ICD-11 criteria for PGD, derived from previously validated scales. The second scale is the *cultural supplement* which includes 19 items gathered from key informant interviews health care professionals working in the field of bereavement from German-speaking and Chinese speaking samples. The cultural supplement is meant to include a wide range of items that span the grief experience within and between cultures. Additionally, we conducted a focus group with four German-speaking bereaved individuals to further explore the acceptability of the ICD-11 PGD items and to identify any missing items.

2.2. Part 2 IPGDS psychometric properties

2.2.1. Recruitment and procedure

See **Table 1** for demographic characteristics of the sample (Stelzer et al., under review). In order to be eligible to participate in the study participants had to experience the death of a loved one, no current diagnosis of serious mental disorder (active psychosis, major depressive disorder, dementia) and not currently participating in grief therapy, for example ongoing psychotherapy sessions. German-speaking participants were recruited within Germany, Austria and German-speaking part of Switzerland. Chinese participants were recruited only in mainland China. German-speaking participants were invited to complete the online survey through various web-based and public platforms (e.g., flyers, posters) including local organizations (e.g., bereavement organizations or grief support groups who shared the study information with their members), community outreach at churches and community centres, University mailing list service and online forums for grief and bereavement. Chinese-speaking participants were recruited through web-based platforms (e.g., online social media [i.e., Wechat] and online memorial forums for bereaved people). Participants accessed an online link to the survey, however prior to starting the survey, they were able to review study goals, risks and benefits and informed consent was obtained. The study took approximately 1.5h–2 h (German-speaking sample: $M = 2.04$ h, $SD = 0.2$; Chinese sample: $M = 1.61$ h, $SD = 0.32$) to complete. Although all data was collected completely anonymously (no identifying personal information was provided by or collected from the participants) the study received ethical approval from the University of Zurich, Switzerland and Beijing Normal University, China.

2.2.2. Participants

Data from participants who completed at least 50% of the survey (214 German-speaking participants and 325 Chinese participants ($N = 539$)) was analyzed. The majority of the Chinese sample were young adults ($M = 33.14$, $SD = 12.30$) women (66%) who were highly

Table 1

Demographic information Note. ¹ Total: 530, German-speaking: 214, Chinese: 316; ² Total: 537, German-speaking: 212, Chinese: 325; ^a 7-point Likert scale from 1 (not at all) to 7 (very much); ^b Score comprised of 13 standard items; ^c Score comprised of standard scale and cultural supplement (32 items). ^d 19 items of the cultural supplement. No time criteria included for IPGDS sum scores. Two-samples Wilcoxon rank sum test was calculated when assumptions of normality were violated. Fisher's exact test is reported for cell counts < 5.

| Variable | German-speaking sample (n = 214) | | Chinese sample (n = 325) | | Total sample (N = 539) | | Difference test |
|--|-------------------------------------|--------|--------------------------|--------|------------------------|--------|--|
| | M / n | SD / % | M / n | SD / % | M / n | SD / % | |
| Age (in years) ¹ | 38.71 | 16.02 | 33.14 | 12.30 | 35.39 | 14.17 | W = 39,105, p = .002 p < .001 |
| Gender | | | | | | | |
| Male | 33 | 15.4 | 104 | 32.7 | 137 | 25.8 | p < .001 |
| Female | 178 | 83.2 | 212 | 66.7 | 390 | 73.3 | |
| Other | 3 | 1.4 | 2 | 0.6 | 5 | 0.9 | |
| Education | | | | | | | p < .001 |
| Primary, high school, vocational education | 111 | 52.1 | 61 | 18.9 | 172 | 32.1 | |
| College/university | 92 | 43.2 | 259 | 80.4 | 351 | 65.6 | |
| Other | 10 | 4.7 | 2 | 0.6 | 12 | 2.2 | $\chi^2 = 74.28, p < .001$ |
| Relationship to deceased | | | | | | | |
| Partner | 35 | 16.4 | 14 | 4.3 | 49 | 9.1 | |
| Child | 32 | 15.0 | 9 | 2.8 | 41 | 7.6 | W = 29,926, p = .010 $\chi^2 = 42.00, p < .001$ |
| Sibling | 11 | 5.1 | 10 | 3.1 | 21 | 3.9 | |
| Parent | 46 | 21.5 | 96 | 29.5 | 142 | 26.3 | |
| Grandparent | 47 | 22.0 | 143 | 44.0 | 190 | 35.2 | W = 35,787, p = .558 t = -7.198, p < .001 |
| Other family member | 17 | 7.9 | 33 | 10.2 | 50 | 9.3 | |
| Friend | 23 | 10.7 | 18 | 5.5 | 41 | 7.6 | |
| Other | 3 | 1.4 | 2 | 0.6 | 5 | 0.9 | t = -6.099, p < .001 |
| Time since loss (in months) ² | 47.67 | 52.52 | 55.18 | 46.27 | 52.22 | 48.92 | |
| Cause of death | | | | | | | |
| Natural death | 154 | 72.3 | 277 | 85.8 | 431 | 80.1 | t = -4.798, p < .000 |
| Accident, drug use | 20 | 9.4 | 22 | 6.8 | 42 | 7.8 | |
| Suicide, murder | 39 | 18.3 | 12 | 3.7 | 51 | 9.5 | |
| Other | – | – | 14 | 4.3 | 14 | 2.6 | t = -4.798, p < .000 |
| Expectedness of death ^a | 3.64 | 2.34 | 3.53 | 2.28 | 3.57 | 2.30 | |
| Prolonged grief: Standard scale (IPGDS) ^b | 29.22 | 10.83 | 36.29 | 11.35 | 33.48 | 11.66 | |
| Prolonged grief: Standard scale + cultural supplement (IPGDS) ^c | 64.05 | 23.81 | 77.40 | 26.39 | 72.10 | 26.20 | t = -4.798, p < .000 |
| Prolonged grief: cultural supplement (IPGDS) ^d | 34.82 | 13.30 | 41.11 | 16.25 | 38.61 | 15.65 | |

educated (80% college or university). The most frequently reported type of loss was loss of a grandparent (44%), or parent (29%) due to natural causes (86%). Most participants lost their loved one less than 10 years ago (94%). The German-speaking sample was also mostly female (83%) young adults ($M = 38.7$, $SD = 16.02$), educated at the level of college or university (43%). The majority of German-speaking participants lost a parent (21.5%) or grandparent (22%), due to natural causes (72%). A detailed descriptive information for the samples is presented in Table 1.

2.2.3. Measures

International ICD-11 Prolonged Grief Disorder Scale: IPGDS Prolonged grief symptoms were evaluated through the ICD-11 Prolonged Grief Disorder Scale (IPGDS) (Killikelly and Maercker, 2017). This scale comprises 13 previously used items integrating the PG-13 (Prigerson and Maciejewski, 2007) and the SCI-CG (Bui et al., 2015). The participants indicated how often they felt preoccupation, yearning and symptoms of emotional distress over the past month because of loss of a loved one, using a 5-point scale: 1 = almost never (less than once a month), 2 = rarely (monthly), 3 = sometimes (weekly), 4 = often (daily), and 5 = always (several times a day). An impairment item as well as screening items (for the length of time since bereavement and the violation of socio-cultural norms) were also included.

Inventory of Complicated Grief (ICG-R 19 item) The Inventory of Complicated Grief-Revised (ICG-R) (Prigerson et al., 2009; Prigerson and Jacobs, 2001) was used to assess emotional, cognitive, and behavioral grief reactions following the death of a loved one, such as yearning for the deceased, preoccupation, or avoidance of loss reminders. Participants rated 15 items on a five-point scale, in addition to functional and duration criteria.

Patient Health Questionnaire (PHQ-9) The Patient Health Questionnaire (PHQ) is a self-administered version of the PRIME-MD diagnostic instrument for common mental disorders (Kroenke et al., 2001). The PHQ-9 is the depression module, which scores each of the 9 DSM-IV criteria as “0” (not at all) to “3” (nearly every day).

Generalized Anxiety Disorder Screener (GAD-7) The 7-item Generalized Anxiety Disorder Scale (GAD-7) is a practical self-report anxiety questionnaire that proved valid in primary care according to DSM-IV (Spitzer et al., 2006). Scores for all 7 items range from 0 (not at all) to 3 (nearly every day). The total GAD-7 score is calculated by simple addition of the answers to each item (min: 0 to max: 21).

International Trauma Questionnaire (ITQ) is the ICD-11 based post-traumatic stress disorder (PTSD) measure (Cloitre et al., 2018). It includes items related to both PTSD and cPTSD (complex PTSD) in the full 18 item scale. The first 9 items of the scale relate to core symptoms of PTSD including re-experiencing, avoidance and sense of current threat and functional impairment, while the remaining 9 items assess affective dysregulation, negative self-concept and disturbances in relationships. For the purposes of this current study we used only the first 9 items to assess PTSD. The psychometric validity of the ITQ has been assessed with cronbachs α 0.76.

The Somatic Symptom Scale-8 (SSS-8) The SSS-8 was first developed for the DSM-5 field trials (Gierk et al., 2014). It was used to assess the presence and severity of common somatic symptoms. A 5-point response option from 0 (not at all) to 4 (very much) for each SSS-8 item in the recent week is used. The SSS-8 score can, therefore, range from 0 to 32.

3. Statistical analyses

All statistical analyses were performed on SPSS version 23. Descriptive statistics including means and standard deviations are presented. Statistical analysis was performed on the 13-item scale and the 32 item scale separately, and separately for German-speaking and Chinese samples. Comparison between groups was conducted with t-tests, ANOVA or χ^2 . The factor structure of the scale was examined using exploratory factor analysis (EFA). Two Exploratory Factor Analysis (EFA) for the German-speaking and Chinese samples were conducted. The first EFA included 13 items of the IPGDS standard scale, and the second one included 32 items (see Table 4). The cultural caveat (item 14) was considered as a screening item and, thus, was not included in EFA. The functional impairment item 13 was included to allow comparison with previous validation studies (Boelen and Smid, 2017). Principal Axis Factoring was chosen as an extraction method. The factors were rotated using the oblique rotation method “Direct Oblimin” allowing the factors to be correlated. The factor number was determined by combining eigenvalue, scree plot and parallel analysis. Parallel analysis was done by Monte Carlo PCA software (by Marley W. Watkins). For all analyses, KMO test values were above > 0.90 and Bartlett’s tests of sphericity were significant ($p < .001$), indicating EFA can be conducted. Reliability of the scale was assessed through cronbach’s α . Concurrent validity was assessed through zero order correlations between the IPGDS, ITQ, GAD-7, PHQ-9, SSS-8 and the ICG-R. Criterion validity was explored through independent t-tests to compare means on IPGDS score across violent and non-violent types of losses, as well as participants who lost a close person compared to any other. Participants who met criteria for a provisional diagnosis of PGD were compared with participants who did not. As this is provisional diagnostic criteria, this analysis was performed on the whole dataset without screening for the time and culture criteria. Provisional cut-off scores were examined using the receiver operating characteristic analysis (ROC) to assess threshold for the best fit sensitivity and specificity. Sensitivity (high 0.80) and specificity (0.80) was assessed through observation of the ROC curve.

4. Results

4.1. Part 1: ipgds development

The key informant interviews and the focus groups revealed unique items that represent culturally specific symptoms of grief for each culture. Table 2 presents the items that key informants and bereaved focus group members identified as missing from the current ICD-11 PGD definition. Supplementary online material presents the IPGDS standard scale and the cultural supplement. In the cultural supplement it is indicated whether the item was recommended by German-speaking or Chinese participants. Our aim was to gather a wide-ranging number of items across both cultures in order to capture different aspects of emotional, cognitive, and physical variability of grief distress. Table 1 supplementary material displays the mean endorsement of each item for each cultural group (also presented in Stelzer et al., under review).

4.2. Part 2: psychometric properties

Descriptive statistics for the samples are shown in Table 1. Samples differed in terms of several demographic variables including age, gender, education, relationship to the deceased, time since loss, cause of death and IPGDS sum scores. Further analysis of IPGDS scores confirmed that there were no significant differences between men and women across German-speaking and Chinese dataset for sum scores on the total IPGDS, 13-item standard scale, or 19 item cultural supplement (all p values > 0.05). In the German-speaking sample there was a significant difference in IPGDS scores between higher education and high school education groups for all scales (all p values < 0.025). Those

Table 2
Key findings and recommended items for the IPGDS from key informant interviews.

| German-speaking key informants | Chinese key informants |
|---|---|
| Meaninglessness, no purpose in life | Helpless |
| Living in past, no future focus | anxiety |
| Despair | looking for the deceased or remember the past relationship |
| | socialize with others |
| Regret | If he or she want to leave with the deceased. |
| Lack of thrive | behavior such as social functions or socialization could be an indicator there is also a meaningless emotion or cognition. hopeless |
| Somebody pulled the rug out from under the feet | cognitive function related and desperate related items |
| Intrusions, closeness to deceased | Somatic/physical symptoms |
| | be balled up or dissociation/paralysis |
| Lack of control in one's life | |
| Lack of trust in world | |
| Physical desire for deceased | |
| Wish to be reunited with the deceased | |
| Looking for the deceased | |
| Suppression of feelings due to personal expectations and cultural norms | |
| Stuck in grief, symptoms did not change | |
| Somatic/physical symptoms | |
| Dissociation/paralysis | |
| Inability to develop or maintain satisfying relationships | |

in higher education group had a significantly higher mean for IPGDS sum score compared to those with high school education. However, the reverse was true for the Chinese sample: those in the high school group had significantly higher means than the higher education group for the IPGDS measure (all scales) (all p values < 0.005). In the German-speaking sample there was a significant positive correlation between age and IPGDS total ($r = 0.14, p < .05$) and IPGDS cultural supplement ($r = 0.14, p < .05$). In the Chinese sample there were significant positive correlations between age and all IPGDS scales (13-item $r = 0.36, p < .00$, total ($r = 0.33, p < .00$), 19-item ($r = 0.29, p < .00$). This indicates that as age increased IPGDS sum score increased.

4.3. Screening analysis

There are two questions of the IPGDS that should be considered screening items; the time criteria (death of a close person at least 6 months ago) and the cultural caveat (item 14: ‘I consider my grief as more intense, severe and/or of longer duration than what is expected in my culture’). For item 14 answers were considered endorsed if they participant scored 3 or higher. When both screening items are applied to the data, 88 German-speaking participants and 152 Chinese participants fulfilled the criteria. A comparison of participants who did or did not endorse the cultural caveat items found that those who experienced grief beyond the cultural norms had higher scores on the IPGDS (see Table 3).

4.4. Diagnostic algorithm comparison

As this scale is newly developed the diagnostic threshold for PGD has yet to be determined. Currently in the literature several different diagnostic algorithms are used. We have examined three frequently cited algorithms to approximate prevalence rates and guide possible diagnostic thresholds. PGD *strict* criteria requires the fulfillment of the following criteria: one of items 1 or 2, 1 or more of items 3–12 and the impairment criteria (item 13) all rated 4 or above (Lenferink et al., 2019). PGD *moderate* criteria is the same as the strict criteria except all items are rated 3 or above. Finally, the Maciejewski et al. (2016) criteria includes one of items 1 or 2, 3–5 of items 3–12 and no impairment

Table 3

Diagnostic algorithm comparison Note. *Percentages calculated based on $N = 191$ German-speaking participants and $N = 305$ Chinese participants who met the time criteria of a loss more than 6 months prior.

| | German-speaking Sample total: 191 | | | Chinese Sample total: 305 | | |
|---|-----------------------------------|------------------------|--------------------------|---------------------------|------------------------|--------------------------|
| | No to cultural caveat | Yes to cultural caveat | P value | No to cultural caveat | Yes to cultural caveat | P value |
| IPGDS standard Sum score (items 1–13) | 23.9 | 33.3 | .000 | 28.4 | 43.4 | .000 |
| IPGDS total 32 items | 51.1 | 73.6 | .000 | 59.6 | 94.0 | .000 |
| IPGDS cultural supplement | 27.1 | 40.3 | .000 | 31.1 | 50.6 | .000 |
| *Prolonged grief disorder after ICD-11 Strict (% , n) | 0.5, 1 | 7.3, 14 | χ^2 : 14.633, 0.000 | 0.6, 2 | 12.7, 39 | χ^2 : 38.85, 0.000 |
| *Prolonged grief disorder after ICD-11 Moderate (% , n) | 4.1, 8 | 19.8, 38 | χ^2 : 32.55, 0.000 | 5.2, 16 | 34.7, 106 | χ^2 : 111.64, 0.000 |
| *Prolonged grief disorder after Maciejewski et al. (2016) (% , n) | 3.14, 6 | 14.6, 28 | χ^2 : 21.9, 0.000 | 5.2, 16 | 30.4, 93 | χ^2 : 85.4, 0.000 |
| ICG-R sum total (19 item) | 27.4 | 41.0 | .000 | 29.3 | 46.9 | .000 |

criteria, all rated 4 or higher (Maciejewski et al., 2016). As evident from Table 3, 7.3% of the German-speaking and 12.7% of the Chinese sample met criteria for the strict definition of PGD. 19.8% of the German-speaking and 34.7% of the Chinese sample met criteria for the moderate definition of PGD. 14.6% of the German-speaking and 30.4% of the Chinese sample met criteria for Maciejewski's definition of PGD.

4.5. Item reduction and factor structure of the ipgds

The EFA with 13 core IPGDS items revealed three factors with initial eigenvalues greater than 1.0 within the German-speaking sample. The first factor had an initial eigenvalue of 6.339 and accounted for 48.8% of explained variance, second and third factors had initial eigenvalues of 1.280 and 1.011 and accounted for 6.2% and 4.2% of explained variance, respectively (open access material available on request). By combing the results from scree plot and parallel analysis (open access material available on request), one factor was retained. Importantly, factor loadings of all items except for item 6 (0.34) were above 0.40 in the one-factor solution. Thus, one-factor solution was deemed to be “fair” (Costello and Osborne, 2005; Williams et al., 2010).

In the Chinese sample, EFA with 13 core IPGDS items revealed two factors with initial eigenvalues greater than 1.0, i.e. 7.172 and 1.084. Both factors accounted for 57.9% of total explained variance (i.e. 52.2% and 5.7% of explained variance, respectively). Aligned with the results of EFA for German speaking sample, scree plot and parallel analysis indicated a one-factor solution (open access material available on request), and all item loadings were above 0.4 (see Table 4).

The second EFA, which included 32 IPGDS items, revealed four factors with initial eigenvalues greater than 1.0 in the German-speaking sample (i.e. 14.951, 2.304, 1.803, 1.134) and three factors (eigenvalue > 1.0) in the Chinese sample (i.e. 16.974, 2.388, 1.494). In the German-speaking sample, the total explained variance was 57.6%. Of interest, when the common variance was considered, only three factors had an eigenvalue greater than 1.0. In the Chinese sample, three factors accounted for 61.6% of total explained variance. The Scree plot and parallel analysis suggested a two-factor solution for both samples (SOM Fig. 3 and Fig. 4). The factor one mainly consists of culturally specific symptoms, and the second factor is mainly made up of grief-related symptoms (see Table 4). An examination of the specific factor loadings provided preliminary guidance for item reduction of the culturally specific items. The following items showed inconsistency across the factors and between the samples. This was determined through visual observation of the data and consultation with expert in research team (AM) in terms of the lack specificity of the item and lack of goal for treatment. Items 15, 16, 28, 30, 31 are recommended for removal. This reduces the cultural supplement to 12 items.

4.6. Reliability of the ipgds

Cronbach's α revealed strong internal consistency for the IPGDS across the whole measure (32 items) for both the German-speaking (0.96) and Chinese (0.97) samples. For the standard scale (13 items) reliability was also strong for the German-speaking (0.92) and Chinese (0.93) as well as the cultural supplement (19 items) German-speaking (0.94) and Chinese (0.96).

4.7. Concurrent validity of the ipgds

Table 5 shows the correlations between the IPGDS sum score and other measures of mental distress including another measure of grief (ICG-R), depression (PHQ-9), anxiety (GAD-7), somatic distress (SSS-8) and trauma (ITQ). For both the German-speaking and Chinese samples strong positive correlations in the expected direction were found between the IPGDS and scores on all measures of psychopathology. All were statistically significant. Higher scores on the IPGDS and higher scores on the other measures indicate higher levels of distress.

4.8. Criterion validity

The IPGDS was assessed in terms of the ability to differentiate between participants who experienced violent or nonviolent losses. It would be expected that those who experienced a violent loss would have higher severity of grief scores (Kristensen et al., 2012). A new variable was created with non-violent loss compared to violent loss (containing loss variables of accident, suicide, drug use, murder or manslaughter and natural disaster). Across the German-speaking sample 154 participants experienced a non-violent and 59 a violent loss (1 missing data). Across the Chinese sample, 277 experienced a non-violent loss and 34 a violent loss (14 missing data). Table 6 shows that the severity of scores on all the IPGDS scales are higher in the violent loss group however this is only statistically significant in the Chinese group. The IPGDS was also assessed to compare different types of losses, for example, those who experience the loss of a close person should experience more severe grief symptoms than those who lose a more distant relationship. A new variable was created *close person* which included spouse/romantic partner, child, siblings, parent compared to *other* which included ex-spouse or romantic partner, grand parent, other family members, friends, other relationship. Across the whole sample 248 participants experienced the loss of a close person (German-speaking sample $n = 122$, Chinese sample $n = 126$) and 291 the loss of another (German-speaking sample $n = 92$, Chinese sample $n = 199$). Table 6 shows that scores on the IPGDS for the loss of a close person which is statistically significantly higher than for the loss of another person.

Table 4

Exploratory factor analysis including cultural supplement items of the International Prolonged Grief Disorder Scale and summary of factor analyses for German-speaking and Chinese sample Note. Extraction method: Principal Axis Factoring; Factor loadings are all direct oblimin rotated loadings; ipgds = International Prolonged Grief Disorder Scale. Note. Extraction method: Principal Axis Factoring; Factor loadings are all direct oblimin rotated loadings; ipgds = International Prolonged Grief Disorder Scale.

| Items | Factor loadings | | | |
|--|-----------------|----------|----------|----------|
| | Chinese | | Swiss | |
| | Factor 1 | Factor 2 | Factor 1 | Factor 2 |
| ipgds_1. "I am longing or yearning for the deceased." | –0.146 | 0.933 | 0.167 | 0.678 |
| ipgds_2. "I am preoccupied with thoughts about the deceased or circumstances of the death." | –0.126 | 0.911 | 0.301 | 0.533 |
| ipgds_3. "I have intense feelings of sorrow, related to the deceased." | | 0.902 | 0.313 | 0.685 |
| ipgds_4. "I feel guilty about the death or circumstances surrounding the death." | 0.161 | 0.562 | 0.248 | 0.26 |
| ipgds_5. "I am angry over the loss." | 0.41 | 0.256 | 0.162 | 0.491 |
| ipgds_6. "I try to avoid reminders of the deceased or the death as much as possible." | 0.129 | 0.353 | 0.351 | |
| ipgds_7. "I blame others or the circumstances for the death" | 0.399 | 0.278 | 0.126 | 0.337 |
| ipgds_8. "I have trouble or just don't want to accept the loss." | | 0.717 | 0.267 | 0.553 |
| ipgds_9. "I feel that I lost a part of myself." | 0.124 | 0.746 | 0.381 | 0.526 |
| ipgds_10. "I have trouble or have no desire to experience joy or satisfaction." | 0.399 | 0.435 | 0.631 | 0.261 |
| ipgds_11. "I feel emotionally numb." | 0.542 | 0.164 | 0.625 | 0.148 |
| ipgds_12. "I have difficulties engaging in activities I enjoyed prior to the death." | 0.522 | 0.167 | 0.638 | 0.289 |
| ipgds_13. Grief significantly interferes with my ability to work, socialize or function in everyday life *item 14 cultural screening item not included in analysis | 0.537 | 0.338 | 0.837 | |
| ipgds_15. I experience strong physical problems since the loss | 0.41 | 0.328 | 0.612 | 0.134 |
| ipgds_16. I would do anything to feel close to the deceased | 0.385 | 0.411 | | 0.703 |
| ipgds_17. Since the loss my behavior has changed drastically in an unhealthy direction | 0.838 | –0.166 | 0.697 | –0.119 |
| ipgds_18. The loss shattered my trust in life or faith in a higher spiritual power | 0.781 | –0.142 | 0.349 | 0.312 |
| ipgds_19. It is impossible for me to focus. | 0.892 | | 0.711 | |
| ipgds_20. My grief is so intense that I feel stuck in grief (I'm stuck in my grief). | 0.555 | 0.352 | 0.588 | 0.296 |
| ipgds_21. I just can't seem to fall back into a rhythm | 0.816 | | 0.82 | |
| ipgds_22. I feel paralyzed and disconnected | 0.872 | | 0.838 | |
| ipgds_23. I have no energy or desire to engage in activities | 0.773 | | 0.777 | |
| ipgds_24. This life holds no meaning since the death | 0.871 | | 0.678 | 0.104 |
| ipgds_25. I want to die in order to be with the deceased | 0.691 | 0.127 | 0.644 | |
| ipgds_26. I don't feel close to other people or feel no satisfaction when being around others. | 0.739 | | 0.853 | |
| ipgds_27. I feel like I have completely lost control over my own life | 0.835 | | 0.907 | –0.231 |
| ipgds_28. I am searching for the deceased with the hope to find him/her | 0.457 | 0.33 | 0.423 | 0.227 |
| ipgds_29. I constantly look back upon the past relationship | | 0.723 | 0.431 | 0.375 |
| ipgds_30. I feel so helpless since I lost him/her. | 0.376 | 0.522 | 0.742 | 0.156 |
| ipgds_31. I feel he/she is beside me. | | 0.627 | –0.232 | 0.561 |
| ipgds_32. I cry loudly when I think of the loss. | 0.22 | 0.561 | 0.336 | 0.433 |
| ipgds_33. I can't trust others since the loss. | 0.765 | | 0.657 | |

Table 5

Concurrent validity Note. ** Correlation between IPGDS sum score and other variable is significant at the 0.01 level (2-tailed). * German-speaking $N = 205$, Chinese $N = 310$.

| | IPGDS Total (32 items) sum score | Standard (13 items) sum score | Cultural supplement (19 items) sum score |
|---------------------------|--|----------------------------------|---|
| German-speaking Sample | | | |
| ICG-R | .921** | .856** | .909** |
| PHQ-9 | .787** | .670** | .825** |
| GAD-7 | .678** | .596** | .697** |
| SSS-8* | .508** | .458** | .514** |
| ITQ | .545** | .542** | .511** |
| Chinese Sample | | | |
| ICG-R | .924** | .860** | .900** |
| PHQ-9 | .783** | .679** | .797** |
| GAD-7 | .617** | .537** | .626** |
| SSS-8* | .538** | .480** | .540** |
| ITQ | .515** | .498** | .422** |

4.9. Comparison of provisional PGD diagnosis and no diagnosis

Participants were grouped into two groups; those who met provisional strict diagnosis for PGD (see diagnostic algorithm comparison section) and those without. Before the screening items (time and culture criteria) are applied, in the German-speaking sample 25 participants met criteria for strict PGD diagnosis and 44 Chinese participants. All

participants with a provisional (strict, moderate or Maciejewski 2016) PGD diagnosis had statistically significant higher scores on the IPGDS. See Table 6.

4.10. Provisional cut-off scores

The Receiver Operating Characteristic analysis (ROC analysis) was used to determine a cut off score for those participants meeting the strict criteria. Results on the whole scale 32 items suggest that for the German-speaking participants a score of 72.5 or above yields a sensitivity of 0.96 and a specificity of 0.778. Whereas for Chinese participants a sum score of 91.5 yields a sensitivity of 0.886 and a specificity of 0.786. For the 13-item scale for the German speaking participants a score of 38.5 yields a sensitivity of 0.93 and specificity of 0.89 and for Chinese participants a score of 42.5 yields sensitivity of 0.90 and specificity of 0.84.

5. Discussion

This study developed a new measure for ICD-11 PGD and assessed its validity. This is the first measure of disordered grief based exclusively on the ICD-11 definition of PGD, additionally it is the first measure to include culturally relevant items of grief. Using key informant interviews and a focus group with bereaved individuals 19 new items were added in the form of a *cultural supplement*. These items were assessed across both Chinese and German-speaking participants with the aim to consider a wide-range of symptoms and to explore if

Table 6

Criterion Validity Note. Independent t-tests performed to compare means on IPGDS scores to section 1 violent and non-violent types of losses, section 2 close person or other person, section 3 PGD diagnosis (strict) or no diagnosis. * Borderline significance, ** statistical significance $p < .05$. Independent t-tests performed to compare means on IPGDS score for provisional strict diagnosis and performed on data set before time and cultural caveat criteria fulfilled.

| Scale | German-speaking | | | Chinese | | |
|------------------|------------------|---------|---------|------------------|---------|---------|
| | Non-violent | Violent | P value | Non-violent | Violent | P value |
| Section 1 | | | | | | |
| IPGDS total | 63.9 | 65.1 | .658 | 75.7 | 84.9 | .052* |
| IPGDS 13 | 28.7 | 30.5 | .233 | 35.7 | 38.5 | .208 |
| IPGDS 19 | 34.9 | 34.5 | .828 | 40.00 | 46.6 | .023** |
| ICG-r | 35.2 | 36.2 | .641 | 37.5 | 44.0 | .013** |
| Section 2 | Close | Other | P value | Close | Other | P value |
| IPGDS total | 70.5 | 55.3 | .000 | 91.0 | 68.7 | .000 |
| IPGDS 13 | 31.9 | 25.6 | .000 | 42.2 | 32.5 | .000 |
| IPGDS 19 | 38.6 | 29.7 | .000 | 48.8 | 36.2 | .000 |
| ICG-r | 39.8 | 29.5 | .000 | 46.5 | 33.6 | .000 |
| Section 3 | PGD Diagnosis | No | P value | PGD Diagnosis | No | P value |
| IPGDS total | 106.4 | 58.4 | .000 | 116.9 | 71.2 | .000 |
| IPGDS 13 | 46.1 | 26.9 | .000 | 52.7 | 33.7 | .000 |
| IPGDS 19 | 60.32 | 31.4 | .000 | 64.2 | 37.4 | .000 |
| ICG-r | 57.0 | 32.5 | .000 | 57.8 | 35.6 | .000 |
| PHQ-9 | 16.2 | 5.04 | .000 | 15.3 | 6.1 | .000 |
| GAD-7 | 12.2 | 5.02 | .000 | 11.7 | 5.6 | .000 |
| ITQ | 11.8 | 4.8 | .000 | 9.3 | 5.4 | .000 |

culturally relevant items could be validly included across and between cultures.

Overall the preliminary psychometric properties including internal consistency, concurrent validity, criterion validity for the full scale (32 items), standard scale (13 items) and the cultural supplement (19 items) were strong. The factor structure supports a one factor or one-dimensional standard scale and a cultural supplement with core grief items and culturally specific items.

5.1. Standard scale

The 13 items representing the narrative definition of PGD in the ICD-11 were based on previously validated scales (Bui et al., 2015; Prigerson et al., 2008). Here we confirm that in both German-speaking and Chinese samples the standard scale of core criteria are valid. The items of the standard scale loaded on to one factor, confirming the one-dimensional nature of the current scale, as found in previous research (Boelen and Smid, 2017; Prigerson et al., 1995). Associations between the standard scale and other validated measures of mental disorder were all significant and in the expected direction i.e. higher scores on the IPGDS indicating worse grief symptoms were associated with worse symptom scores on other measures of disorder. This was true for both Chinese and German-speaking samples. Additionally, measures of criterion validity are confirmed for the Chinese sample and partially confirmed for the German-speaking sample. It was expected that those who experienced the death of a close relative or a violent death would have higher scores on the IPGDS (Kristensen et al., 2012). Similar to previous grief scale validation studies (Boelen et al., 2019; Boelen and Smid, 2017) we found the above to be true and all of the sum scores on the IPGDS were in the expected high direction for these subgroups. However, when considering violent loss this was only statistically significant for the Chinese sample; sum scores on the IPGDS were significantly higher for Chinese participants experiencing violent loss. This could be due to sample differences. The German-speaking sample included a higher number of individuals bereaved by suicide, however they were members of support groups. It could be these individuals are

less impacted by the nature of the loss because they received psychosocial support (Spino et al., 2016). This may not be true for the Chinese bereaved in our sample (Li and Chen, 2016).

5.2. Cultural supplement

The EFA indicated that by including the cultural items this yielded two different factors for both the Chinese and German-speaking data. Interestingly, factor one loads with accessory items and culturally specific items, whereas factor two loads primarily with the core features (first three items) of the standard scale. The full scale could therefore capture both pan-cultural core items of grief along with culturally relevant items.

Interestingly, even though items were derived from specific recommendations from each cultural group all items of the cultural supplement could be validly assessed in Chinese and German-speaking populations. However, there are some important caveats. There was a significant difference between cultural groups in the sum scores on the IPGDS standard scale (13 items) and the full scale including the cultural supplement (32 items) as well as the preliminary diagnostic prevalence. On both scales the Chinese sample indicated higher grief symptoms. This has been reported in other studies with Asian samples (Stelzer et al., 2020c; Xiu et al., 2016). There could be several explanations for these higher scores. Interestingly, here we see higher scores even when culturally specific items are included. The current high scores could be explained by sample differences derived from methods of recruitment. Firstly, the Chinese sample were significantly younger than the German-speaking sample and perhaps more vulnerable to grief symptoms (Li and Chen, 2016). It could also be related to social expectations and cultural norms around grieving. The cultural norm hypothesis proposes that the expression of mental disorder can be more severe in cultures where emotional expression is usually controlled in public. It was previously found that when comparing depression symptoms between European Americans and Asian Americans, European Americans ‘dampened down’ their emotional expression when depressed whereas Asian Americans presented with elevated emotional reactivity (Chentsova-Dutton et al., 2007). In both cases individuals acted in ways which violated socio-cultural norms, and for the Asian-Americans, this was an ‘over’ expression (Chentsova-Dutton et al., 2010). Another reason could be that Chinese people usually suppress and internalize their feelings and thus may not seek support from support groups or professionals, which could also worsen their grief reactions (Xiu et al., 2016).

5.3. Recommendations for how to use cultural supplement: stepped procedure

Although this study confirms the psychometric validity of the standard and cultural supplement scales of the IPGDS, there are some important considerations for application to a clinical setting. Below we recommend a best practice procedure for utilizing the IPGDS in a mental health setting. The standard IPGDS scale can be used without adaptation across German-speaking and Chinese cultural groups, as is confirmed by the cross-cultural validity established in this study. Importantly there are two screening items (time criteria and cultural caveat item 14) that could be administered before the standard scale. These items should then be considered along with clinical opinion before making a final diagnosis. In terms of diagnostic criteria, the strict algorithm (described in the methods section) is currently recommended as it yields the expected prevalence rates and is confirmed through the criterion validation analysis (e.g. those with a strict diagnosis had statistically higher IPGDS scores). Finally, in terms of the cultural supplement the items validated in the current sample provide a more in-depth assessment of grief symptoms and are endorsed across both German-speaking and Chinese samples.

6. Limitations

Due to a small sample size it was not possible to perform additional analysis of item response theory or to further explore the structure of the IPGDS. Additionally, sample differences between the Chinese and German-speaking participants are difficult to interpret. All items of the cultural supplement were evaluated across both Chinese and German-speaking participants. Further research should examine if there are Chinese or German-speaking specific items that are more representative of each group using item response theory in a larger sample size. Further validation of the diagnostic thresholds is required however this is currently limited as there is not consensus across the field in terms of the appropriate diagnostic algorithm. Finally, the criterion validity of the scale should be assessed in a sample with a larger number and variety of participants. For example, the sample mainly consists of young adults rather than middle- or old- aged adults who may lose a spouse or child, whereas the developmental stage and type of loss could influence post-loss adaption and grief severity. In addition, the non-significant difference of IPGDS scores between violent and non-violent losses in the German speaking sample only, could indicate that the scale is differentially assessing grief severity in the German-speaking and Chinese samples. However, perhaps a more parsimonious explanation is the study sampling method did not include German speaking participants who were currently experiencing the effects of violent loss, as indicated above.

7. Conclusion

Here we developed the new IPGDS measure of PGD for the ICD-11. Our preliminary validation study confirms that the standard scale and the cultural supplement can be used in both German-speaking and Chinese samples. The standard scale is recommended for use in clinical settings in order to capture ICD-11 PGD symptoms. The cultural supplement may be used to further evaluate symptoms of PGD in diverse cultural groups to explore the range of grief symptoms.

Author statement

CK conceptualized the study and analysis, conducted the psychometric analysis and wrote the manuscript. NZ and MM conducted the EFA analysis. ES and NZ managed the data collection for qualitative and questionnaire data and conducted qualitative data analysis. MM, TD, SR, HS assisted data collection and data analysis. AM assisted with writing the manuscript and conceptualization.

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Declaration of Competing Interest

None.

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Supplementary materials

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